

Northeastern University, Social Science Environmental Health Research Institute

Name of Investigator(s): PI, Phil Brown; Co-PI Alissa Cordner

Title of Project: Perfluorinated Chemicals: The Social Discovery of a Class of Emerging Contaminants

Informed Consent to Participate in a Research Study

We are inviting you to take part in a research study. This form will tell you about the study, but the researcher will explain it to you first. You may ask this person any questions that you have. When you are ready to make a decision, you may tell the researcher if you want to participate or not. You do not have to participate if you do not want to. If you decide to participate, the researcher will ask you to sign this statement and will give you a copy to keep.

Why am I being asked to take part in this research study?

We are asking you to participate in this assessment because you either lived in an area affected by poly- and perfluoroalkyl substances (PFASs), are a scientist studying those chemicals, are a government official involved in dealing with those chemicals, an official in a corporation producing or using those chemicals, a lawyer who is part of a case involving those chemicals, or a member of an environmental health organization concerned with those chemicals.

Why is this research study being done?

The purpose of this research is to understand the discovery of poly- and perfluoroalkyl substances (PFASs), their use in industrial production, effects on individuals and communities, and scientific, regulatory, corporate, and advocacy action to restrict their use.

What will I be asked to do?

If you decide to take part in this study, we will ask you to take part in an interview (in person or by phone) that will last between 30-60 minutes. We will ask you questions about: your personal and organizational involvement in an issue concerning PFASs.

Where will this take place and how much of my time will it take?

You will be interviewed in person or over the phone. We encourage you to complete the interview in a private place, using a private phone line. The interview will take about 30-60 minutes.

Will there be any risk or discomfort to me?

No significant personal risks are anticipated.

Will I benefit by being in this research?

No significant personal benefits are anticipated, though you may benefit from having the opportunity to reflect on issues concerning PFASs.

Who will see the information about me?

Unless you specifically allow us to use your real name and affiliations in the space below, your name will not be used in any publications that result from this research. Your part in this study will be confidential.

Only the researchers on this study will see the information about you. No reports or publications will use information that can identify you in any way or any individual as being of this project. Your signed consent form will be retained for 3 years following the end of the study and will be stored in a locked filing cabinet in Principal Investigator Phil Brown's office at Northeastern University.

In the write up of the research results, generic types (e.g. "a researcher" or "a community organization leader") will be always be used instead of names for interviewees, unless you sign your permission to be identified. Personal and case-specific details and information will be altered during write-up to further protect your identity.

We will be using a digital recorder, which stores audio interview files on a small SM card (disk). The audio files will be promptly transferred from the SM Card to firewall and password protected computers, which are kept in locked rooms at all times. Upon successful transfer, the SM Card will be erased in a secure fashion. Storing these recordings allow members of the research team to transcribe your interview.

All audio files and interview transcripts will be stored in password-protected files on firewall-protected computers and in secure and password protected DropBox files. Interview transcripts will not include your name; instead, we will assign

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each participant a number. Only the research team members will know who is assigned to which number. During write up, the names of participants will be replaced with generic titles, such as "an activist" or "a researcher."

If you feel uncertain about anything during the course of your participation, the interviewer will stop and ask whether or not you would like to continue. There are no penalties for ending participation. You may refuse to answer any question or ask for clarification if needed.

We cannot guarantee total confidentiality. People you live or work with could overhear you on the phone during your interview. While we will exercise all of the security measures and precautions listed above, it is always possible for confidential data to be lost or stolen.

What will happen if I suffer any harm from this research?

While you may experience stress or frustration during the course of the interview, we cannot make special arrangements to compensate or pay for treatment of this discomfort.

Can I stop my participation in this study?

Your participation in this research is completely voluntary. You do not have to participate if you do not want to and you can refuse to answer any question. Even if you begin the study, you may quit at any time.

If you do not participate or if you decide to quit, you will not be penalized.

Who can I contact if I have questions or problems?

If you have any questions about this study, please feel free to contact Principal Investigator Phil Brown at 617-373-7407.

Who can I contact about my rights as a participant?

If you have any questions about your rights in this research, you may contact Nan C. Regina, Director, Human Subject Research Protection, 960 Renaissance Park, Northeastern University, Boston, MA 02115.

Tel: 617.373.4588, Email: n.regina@neu.edu, You may call anonymously if you wish.

Will I be paid for my participation?

We offer no payment for participation in this research project.

Will it cost me anything to participate?

There is no cost. The research team will make the calls from their end or use a free internet-phone service such as Skype.

Is there anything else I need to know?

You must be at least 18 years old to participate.

I agree to take part in this research.

Signature

Date

Printed name

Preference to use real name and organizational affiliation

Signature

Date

Signature of person who explained the study to the participant

Date

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